Original Research Article

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Spectrum of clinical profile, co-morbidities and parental burden of cerebral palsy children in a tertiary care centre

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ABSTRACT

Background: The cerebral palsy is the most common cause of severe physical disability in childhood. The developmental disabilities are a group of disorders differentiated by the pattern of delay among developmental streams. The four streams of development include language, problem solving, motor and social. Cerebral palsy (CP) is a disorder of development in which motor function abnormalities are a key feature. Severity varies from mild to severe. Cerebral palsy is a very challenging disability for parents and professionals. Cerebral palsy is a heterogeneous group of persistent disorders of movement and posture caused by non-progressive defects or lesions of immature brain, is the most common cause of childhood disability. The incidence of CP is 2 to 2.5 per thousand live births. During the past twenty years, there have been increases in the incidence and prevalence of CP that may be related to improved documentation of cases, advances in neonatal care and other factors.

Methods: This study is a cross-sectional study. A total of 100 Cerebral Palsy cases were studied in Neuro-developmental clinic, in BMC and RI.

Results: Clinical profile of our study shows 74% Spastic cerebral palsy cases (of which 38% were quadriparetic, 31% were diplegic and 5% were hemiparetic), 19% of Hypotonic CP, 1% of Dystonic CP and 6% of Mixed CP cases. Co morbidities in the form of Mental retardation was seen in 94%, feeding problem 64%, visual problems in 39%, seizure disorder in 39%, hearing problems in 18%, behavioral problems 16% of cases.

Conclusions: Perinatal asphyxia was important preventable cause of cerebral palsy. Majority of cerebral palsy children were of spastic type. Mental retardation, feeding problem, hearing and vision impairment and seizures were major co morbidities in children with cerebral palsy. Nuclear type of family and high number of co morbidities of the disabled child correlated significantly with higher caregiver burden.

Keywords: Caregiver burden scale, Cerebral palsy, Perinatal asphyxia

INTRODUCTION

The cerebral palsy is the most common cause of severe physical disability in childhood. The developmental disabilities are a group of disorders differentiated by the pattern of delay among developmental streams. The four streams of development include language, problem solving, motor and social. Cerebral palsy (CP) is a disorder of development in which motor function abnormalities are

a key feature. It is a most common developmental disorder of children first described by William little in the 1861. Severity varies from mild to severe. Cerebral palsy is a very challenging disability for parents and professionals. Cerebral palsy is a heterogeneous group of persistent disorders of movement and posture caused by non-progressive defects or lesions of immature brain, is the most common cause of childhood disability. The incidence of CP is 2 to 2.5 per thousand live births. During the past

twenty years there have been increases in the incidence and prevalence of CP that may be related to improved documentation of cases, advances in neonatal care and other factors. Cerebral Palsy has substantial effect on function and health related quality of life of patients and their care givers. Cerebral palsy is a well-recognized neuro developmental condition beginning in early childhood and persisting throughout life.

Cerebral palsy describes a group of permanent disorders of the development of movement and posture causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and/or by seizure disorder.³

Parents are the primary care givers for a child. Care of a CP child requires more attention and longer duration of care compared to care of normal children. This results in burden on parents and it adversely affects the physical and mental health of the parents, which in turn hampers the care needed for Cerebral Palsy child.⁴

With strengthening of obstetric and neonatal care at National level, there is an increased health care facility which has decreased the Neonatal Mortality but Morbidity in survived newborn has increased.⁵

This study helps us to know current status and clinical spectrum of Cerebral Palsy. The study also intends to look into the proportion of the etiologies, co morbidities in cerebral palsy children and parental burden assessment

which helps in addressing the parental issues, thereby improving care for Cerebral palsy children.

METHODS

Cases of Cerebral Palsy were studied over duration of one year between November 2015 to October 2016 in Neurodevelopmental clinic of Bangalore medical college and research institute, Bengaluru. Cases included in the study chosen as per inclusion criteria guided by "The Definition and classification of cerebral palsy, April 2006 International consensus".3 Cases were evaluated by clinical history and clinical examination and necessary investigations using a systematically designed proforma. Thorough clinical history was collected regarding presenting complaints, birth history (antenatal, intranatal and postnatal), developmental history etc in each case. A thorough clinical examination was done, specially the neurological examination and Ophthalmic Otorhinolaryngology examination. Parental burden study was assesed using Care givers burden scale, Zarit burden interview which is the most widely referenced scale in the study of caregiver's burden, which uses questionnaires of 22 items, that reflects how persons sometimes feel when they are taking care of another person. The total score range from 0 to 88, a high score indicates higher level in burden.

RESULTS

1

8

In our study 100 Cerebral Palsy children studied and care giver burden assessed as per care giver burden scale. And we found the following results;

Perinatal Neonatal **Pyogenic Intracranial** Type of CP **Idiopathic** Genetic **Prematurity Total** asph<u>yxia</u> sepsis meningitis bleed Spastic diplegia 2 12 11 1 2 31 1 Spastic 7 1 22 1 3 2 2 38 quadriparesis Spastic 0 2 0 1 1 0 1 5 hemiparesis Hypotonic CP 4 8 3 1 2 1 0 19 Dystonic CP 0 0 1 0 0 0 0 1

1

6

Table 1: Etiology of cerebral palsy children.

Table 1 shows Observed etiologies in our study Prematurity-22%, Perinatal asphyxia-47%, genetic-7%, Intracranial bleed-5%, Post-meningo-encephalitis-8%, Neonatal sepsis-6%, Idiopathic-5%. Table 2 shows Classification of CP with Spastic Diplegia-31%, Spastic Quadriplegia-38%, Spastic Hemiperesis-5%, Hypotonic-19%, Dystonic-1%, Mixed CP-6%. Table 3 shows Co morbidities percentage in Each Type of CP children.

3

47

0

22

0

7

Mixed CP

Total

Table 2: Classification of diagnosis of CP children.

0

5

6

100

1

5

Spastic	Diplegia:	31
	Quadriperesis	38
	Hemiperesis	5
Hypotonic		19
Dystonic		1
Mixed		6

DISCUSSION

Cerebral palsy is a heterogenous group of persistent disorders of movement and posture caused by non-progressive defects or lesions of immature brain. It is the most common cause of childhood physical disability. The incidence of CP is 2 to 2.5/1000 live births. Gestational age of the affected children observed in our study was term gestation in 78%, late preterm (32-36 wk) in 16% and early preterm (28-32 wk) in 6%. 6 out of 22 preterms (27%) had spastic diplegia. Periventricular leukomalacia the

important pathology observed in spastic diplegia is most commonly observed in prematurity.

Birth weight of the affected children: 76% of the children weighed between 2.5 to 4 Kg and 3% of them weighed <1.5 Kg. Low birth weight was observed in 24% of our cases, but prematurity was seen in 22% indicating a 2% of term children were IUGR in our study. CP in children normal birth weight was mainly caused by global ischemia secondary to perinatal asphyxia, cerebral malformation, intracranial bleed and post-natal infections. This was comparable with other studies.⁶⁻⁸

Table 3: Associated problems (Comorbidities) in CP children.

Type of CP	Mental retardation	Seizure disorder	Visual problems	Hearing problems	Speech problems	Behaviour abnormalities	Feeding problems
Spastic diplegia	28	8	13	5	5	7	21
Spastic quadriparesis	35	20	14	4	7	2	23
Spastic hemiparesis	5	2	1	1	0	1	3
Hypotonic CP	19	5	7	4	2	4	11
Dystonic CP	1	1	1	1	1	1	1
Mixed CP	6	3	3	3	0	1	5
Total	94	39	39	18	15	16	64

Table 4: Care giver sample characteristics (n=100).

Variables		0/0
Age of the children (Median) (in months)		
Sex of the child	Male	52
	Female	48
Region	Urban	82
	Rural	18
Mother's age (Median) (in years)		
Education of the care	<sslc< td=""><td>58</td></sslc<>	58
giver	>/= SSLC	42
Socio economic status	Income <5000 rupees	25
	Income >5000 rupees	75
Type of Family	Nuclear	69
	Joint	31
Type of CP	Spastic Quadriplegia	38
	Spastic Diplegia	31
	Others	31
Co morbidities	Mental Retardation	94
	Seizures	37
	Visual problems	39
	Hearing problems	18
	Speech problems	15
	Behavioral abnormality	16
	Feeding Problems	64

In present study 74% of the cases constituted Spastic variety of cerebral palsy which was comparable to SMS Jaipur, Serdaroglu et al and CP in Europe studies.⁶⁻⁸ Quadriparesis was predominant observation in our study

in contrast to national and international observation. Diplegia observed in 31% of cases compared to 54% in Jaipur study and 22% in international study. Hemiparesis constituted 5% in contrast with international observation. Hypotonia was observed in 19% of cases comparable with both SMS Jaipur and international observation. Dystonia in 1% of cases and Mixed cerebral palsy in 6% of cases, both were comparable with SMS Jaipur and CP in Europe studies.

In present study, Spastic Quadriperesis was most common followed by Spastic Diplegia which attributes to Perinatal asphyxia and Prematurity were the major cause

Intellectual subnormality (IQ <70) was observed in 94% of cases, Speech abnormalities were observed in 15% of cases, visual problems were observed in 39% of our cases, Behavioural abnormality was seen in 16%, hearing impairment in 18% of our cases, seizures were observed in 39% of our cases, 64% of the children had feeding problems. Intellectual subnormality and Feeding problems were predominantly observed in Spastic quadriparetic and Hypotonic CP children. That was secondary to global cerebral involvement and cerebral malformations. Seizure was observed predominantly in Spastic quadriparetic cases. Caregiver burden is an important concern among caregivers of children with cerebral palsy. Minimizing caregiver burden can lead to improved mental health outcomes for both caregiver and child. The parental burden in our study shows significant burden to the parents. In our study, nuclear family associated problems like seizure disorder, visual problems Hearing problems, Behavioral abnormalities and Feeding problems were associated with high parental burden score. A similar study on parental burden (Asia pacific 2015 study) showed significant burden to the parents in relation to following independent variable-Rural area, Low income, Type of CP, Number of functional deficits, and Medical Co morbidities. Our study is comparable with this study in assessment of parental burden in CP children.⁹

Table 5: Association of independent variables with caregiver burden score.

Model	Unstandardized Coefficients		Standardized Coefficients	4	C! ~
Model	В	Std. Error	Beta	L	Sig.
(Constant)	67.251	1.583		42.474	0.000
Age of the child	-9.88E-03	0.008	-0.059	-1.250	0.215
Sex	0.355	0.320	0.058	1.110	0.270
Region	2.895E-03	0.402	0.000	0.007	0.994
Mother's age	-1.15E-02	0.297	-0.002	-0.039	0.969
Education	0.593	0.315	0.095	1.882	0.063
Income	4.947E-02	0.356	0.007	0.139	0.890
Family type	-1.181	0.386	-0.178	-3.063	0.003
MR	-1.048	0.629	-0.081	-1.668	0.099
Seizures	0.646	0.325	0.107	1.989	0.050
Visual problems	1.543	0.475	0.245	3.249	0.002
Hearing problems	3.330	0.470	0.417	7.084	0.000
Behavior	0.237	0.409	0.028	0.581	0.563
abnormality	0.947	0.474	0.113	1.997	0.049
Feeding problems	1.416	0.374	0.221	3.787	0.000
Type of CP	-1.82E-03	0.110	-0.001	-0.017	0.987

CONCLUSION

Spastic quadriparesis was the most common clinical form of cerebral palsy observed in our study mostly secondary to global ischemia during perinatal period which are mostly preventable. This is in contrast to international observation of predominant spastic hemiparetic cerebral palsy which is mostly secondary to nonmodifiable intrauterine vascular insult. Perinatal asphyxia was the important etiological factor in our study. We found preventable intranatal and postnatal events formed significant proportion of our study group.

So, timely obstetrical intervention and immediate proper newborn care can still play a major role in preventing cerebral palsy hence, there is urgent need to further strengthen the existing maternal and child health services. Comorbidities are significantly observed in cases of cerebral palsy. Appropriate screening and management of comorbidities especially vision, hearing, speech, seizures and feeding problems improve the overall prognosis in cases of Cerebral palsy. Seizures add dimension of uncertainity to the otherwise relatively static problem of cerebral palsy. The presence of seizures is associated with

increased risk of cognitive problems and a greater burden of care. Parental burden was high and this can be addressed by minimizing the natal issues, and early recognition of CP and early intervention and stimulation to prevent the co morbidities.

Caregiver burden is an important concern among caregivers of children with cerebral palsy. Minimizing caregiver burden can lead to improved mental health outcomes for both caregiver and child. Since CP is a chronic permanent disability and parents are the primary care takers of a CP child, addressing their burden will have improved outcome in care of CP children.

Supporting the parents by Family members and minimizing the associated Co morbidities (i.e. by early diagnosis, early screening for co morbidities, early stimulation and specific treatment) will lessen their burden and further helps in good care of affected children.

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Institutional Ethics Committee

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